

Project C.A.R.E. –
Caregiver Alternatives to Running on Empty
Lessons for the Future

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Executive Summary

Caregiver Alternatives to Running on Empty (Project C.A.R.E.), initially implemented in July 2001, provides caregiver-focused respite, education and support services to family caregivers of adults with dementia. Project C.A.R.E. is a public-private partnership between the North Carolina Division of Aging and Adult Services (NC-DAAS), Mecklenburg County Department of Social Services (DSS) and Western Carolina Alzheimer's Association. The program is funded through the federal Administration on Aging (AOA) Alzheimer's Disease Demonstration Grants to States Program (ADDGS) and receives technical assistance from the Duke Aging Center Family Support Program. During the first three years of operation, Project C.A.R.E. provided much needed respite support to over 460 families, primarily rural, minority and low-income. An additional 381 families accepted consultation and referral services without respite funding.

The lessons learned from Project C.A.R.E. fall into two major categories: system lessons and client/family-focused lessons. One primary system lesson is that a dementia-specific respite program can be successfully based in an Alzheimer's Association Chapter or a county DSS (with direct links to the expertise and resources of the Alzheimer's Association). This type of flexibility allows different regions to tailor the program to individual needs and strengths. A second system lesson is the pivotal role the Family Consultant plays in the success of both service delivery models. A third system lesson is that a program offering dementia-specific respite care to previously underserved areas and inadequately served families is both feasible and appropriate.

Three client/family-focused lessons also emerged from the experience of Project C.A.R.E. First, consumer-directed respite care offer families preferred control over the services they receive. Second, effective respite support for Alzheimer's families must offer in-home and day program options with flexible frequency and duration to meet family-specific needs and preferences. Finally, respite can and should serve as a portal for families to connect to community resources, information and other available service options such as training, education and counseling.

Introduction

Under the leadership of the North Carolina Division of Aging and Adult Services (NC-DAAS), Project C.A.R.E. fills a vital need for dementia caregivers through the provision of part-time supplemental care, either in the home or in a community group setting. This paper describes Project C.A.R.E.'s delivery of dementia-specific respite services and discusses how the lessons learned during the program's first three years may be incorporated into state long-term care planning.

The successful administration of Project C.A.R.E. by both public and private agencies enables the program to match local strengths and preferences in service delivery. The program is further enhanced by the ability to share resources and create community networks, clearly demonstrating the value of local partnerships as a vital element in building a sustainable support system for dementia families. Project C.A.R.E. addresses the need for dementia-specific respite not available through existing caregiver programs, while simultaneously building upon quality public/private partnerships among community providers. The evolution of Project C.A.R.E. -- from a respite service to a portal for Alzheimer's families to access other community resources

and services -- creates a niche for this program as a key component of an integrated home and community-based aging and adult service system.

Background

The primary goal of Project C.A.R.E. is to improve the quality, access, choice, and use of respite services for families caring in the community for individuals with Alzheimer's disease or related dementia. Project C.A.R.E. focuses on families isolated by economic, geographical and cultural factors. The program is uniquely successful in reaching out and actually serving rural, minority and low-income elders. By targeting limited federal, state and local funds, Project C.A.R.E. strives to maximize family potential to provide "the most appropriate, high quality, cost-effective care in the least restrictive setting." This approach builds directly upon the recommendation of the North Carolina Institute of Medicine Long-Term Care Task Force Report. Project C.A.R.E. also seeks to identify barriers and gaps in services, strengthen linkages between the Alzheimer's Association and community care systems, and incorporate volunteer and faith-based organizations into support networks for dementia families. The program helps family caregivers by providing a Family Consultant who can assist with dementia care issues, connect caregivers with community resources, and coordinate funding to pay for respite care.

There are three Project C.A.R.E. pilot sites set up to serve the following six counties: Forsyth, Polk, Henderson, Transylvania, Rutherford and Mecklenburg. The Western Carolina Alzheimer's Association employs two full-time Family Consultants to implement the program out of regional Chapter offices located in Winston-Salem and Asheville. In Charlotte, Project C.A.R.E. is administered by a part-time Family Consultant within the Mecklenburg County

DSS. The DSS Consultant also works part-time as a Family Caregiver Support Program Specialist.

Project C.A.R.E. is funded through a three-year grant provided by the Administration on Aging (AOA) Alzheimer's Disease Demonstration Grants to States Program (ADDGS). The ADDGS Program was established in 1992 for the purpose of improving the responsiveness of the overall system of home and community-based care to the needs and preferences of persons with Alzheimer's disease and related disorders. The ADDGS program aims to expand the availability of diagnostic and support services for individuals with dementia, their families and caregivers. North Carolina was one of the first "pioneer" states to receive an Alzheimer's demonstration grant. The original state demonstration project, which was funded from July 1993 to June 2000, substantiated the feasibility and effectiveness of community-based group respite programs. Built upon seven years of experience, Project C.A.R.E. was developed and funded in July 2001. By April 2004, Project C.A.R.E. received a "Geriatric Best Practice" award for "Developing Quality Caregiver Support and Respite Programs" by the Geriatric Best Practices Initiative. This southeast regional initiative was sponsored by the SAGE Institute, South Carolina Hospital Association and The Duke Endowment.

During the first year of the grant, North Carolina provided a 25% match to federal ADDGS funding, increasing up to 35% and 45% by the second and third grant year respectively. The annual increase in state matching funds is part of a federal mandate designed to encourage sustainability, promote local buy-in and better position states to continue and/or expand programs beyond the scope of the federal demonstration period. In North Carolina, the state's match requirement is fulfilled in part through a technical assistance and training contract with the Duke Aging Center Family Support Program. Local match is also provided by the Western

Carolina Alzheimer's Association, Mecklenburg County DSS and NC-DAAS through state appropriations, county funds and administrative salary.

Project C.A.R.E: An Overview

Services

Client families enrolled in Project C.A.R.E. are offered a home visit from a Family Consultant with counseling, education and follow up assistance as well as the option of receiving one or all of three different types of respite care: in-home care, adult day services, and overnight residential respite. In the first year of the program, each eligible family received up to \$2,500 a year to cover the cost of respite services. In the Winston-Salem and Asheville program sites, the annual cap was reduced to \$1,800 - \$2,000 in subsequent years to help serve families on increasingly long waiting lists. Some families choose not to receive respite funds and only use the consultation and referral services of the Family Consultant. This type of support is especially helpful for the growing numbers of families trying to coordinate care for a memory-impaired relative from a distance.

If respite funds are spread evenly over one year, a monthly allocation could purchase approximately two four-hour shifts of in-home care per week. Project C.A.R.E. funds go further, however, when purchasing adult day services. With an average daily cost of only \$31 per day, a client family could potentially purchase full time day care for an entire month. Overnight respite in a long-term care facility, as a third option, is rarely used because of the high cost. However, residential respite can provide caregivers with the option of taking a brief family vacation or extended time off to deal with medical problems or a family emergency.

The changing nature of dementia care and family conditions make it difficult to determine the average period of time families will use Project C.A.R.E. services. In part, this is due to the fact that many caregivers do not ask for help until they have reached a “crisis point”. For most Project C.A.R.E. clients, service use averaged approximately eight months. This result is similar to earlier ADDGS national program evaluation data (Montgomery, 2003). Some Project C.A.R.E. families will eventually qualify for more intensive Medicaid Waiver Services through North Carolina’s Community Alternatives Program (CAP). However, the two most common reasons for exiting Project C.A.R.E. to date are facility placement or death of the person with dementia.

Feedback from families receiving Project C.A.R.E. services, most often arriving in the form of letters and testimonials, indicates that the respite support is deeply appreciated and needed. Project C.A.R.E. often makes it possible for caregivers to maintain employment and keep their family member with dementia at home longer. Positive outcomes are also evident in the consistent annual re-enrollment of clients and the relatively high proportion of word-of-mouth referrals. Referrals are frequently received from the Alzheimer's Association Helpline, North Carolina Family Caregiver Support Program, Hospice, DSS, physicians, senior centers, community health centers and others. The large number of referrals from health care providers, faith groups and key community organizations is a good indication that the outreach and public awareness efforts of Project C.A.R.E. are successful.

Resource Sharing and Community Connections

Project C.A.R.E. encourages resource sharing and community connections, an attribute that builds upon, enhances and sustains local service infrastructures. By creating a more seamless

and dementia-friendly care delivery system, non-duplicative resources are available to caregivers and adults with cognitive impairment. Families do not have to "start from scratch" to locate the programs and services relevant to their needs.

According to a summary of the first seven years of the AOA ADDGS Program, successful demonstration projects across the country are those in which capacity-building efforts resulted in community commitment and the creation of new resources (Montgomery, 2003). Community commitment is measured in expanding awareness, especially among ethnic and rural communities. Project C.A.R.E. is successful in both areas of capacity building.

Community Commitment

Project C.A.R.E. creates partnerships with local in-home health agencies, adult day programs and long-term care facilities, integrating both public and private resources. The Project C.A.R.E. Family Consultants connect respite care providers to the expertise and support of the Alzheimer's Association thus providing a variety of opportunities to receive dementia-specific training and educational resources. Increasing knowledge of Alzheimer's disease and dementia care enhances caregiver skills and confidence. Consequently, Project C.A.R.E. increases access to a larger and more diverse network of provider agencies, presenting families with a broad range of choices to meet their specific needs, values and preferences. The program establishes a vital link between dementia families and local home and community-based services. Many private respite providers would not be able to serve vulnerable low socioeconomic families without Project C.A.R.E. funds.

Project C.A.R.E. creates important advantages for the hosting organizations: NC-DAAS, Western Carolina Alzheimer's Association, Duke Family Support Program and Mecklenburg

County DSS primarily through increased visibility of each organization's unique contributions, resources and services within the community and the state. Project C.A.R.E. also heightens public awareness of Alzheimer's disease and the needs of dementia caregivers and enhances the collaborative capacity to create sustainable system change. Local service infrastructures become more dementia-friendly and capable, regardless of where the family enters the system or seeks help.

Creation of New Resources

Another benefit for targeted communities is the dissemination of educational products developed by the Duke Family Support Program with Project C.A.R.E. resources. Some examples include: 1) "Working With Family Caregivers of People With Memory Disorders: A North Carolina Information and Assistance Toolkit" for county aging and adult services staff working directly with dementia families, 2) "Wait a Minute!": brief tips for families on how to handle caregiver anger, 3) an information packet for churches on responding to congregant families coping with dementia and 4) "Steps to Success: Decisions About Help at Home for Alzheimer's Caregivers": an AARP consumer booklet that incorporates Duke's caregiver research. These educational materials are frequently used by Project C.A.R.E. staff as well as other agencies and states.

Project C.A.R.E. facilitates the development of dementia-specific services in communities with little or no presence. For example, the Family Consultant based in Winston-Salem strengthened linkages between the local Alzheimer's Chapter and the African-American community in Forsyth County. In addition to enhancing service delivery and training resources,

Project C.A.R.E. provides necessary leverage for the Alzheimer’s Association to advocate for expanded dementia-specific respite care in North Carolina.

Project C.A.R.E. also integrates faith-based organizations and volunteer groups. Faith in Action (FIA), a national volunteer program with a significant presence and base in North Carolina, is well linked to the Project C.A.R.E. Family Consultants and Area Agency on Agency (AAA) Family Caregiver Resource Specialists. FIA connects volunteers from interdenominational groups to families in need of support services. The Western Carolina Alzheimer’s Association offers faith-based volunteer training and conducts an annual “Faith, Hope and Alzheimer’s Disease” education conference for clergy, families and other interested community members.

Cost Effectiveness

Resource sharing and community connections make Project C.A.R.E. cost-effective in a number of ways. First, the program builds upon the existing state home and community-based care infrastructure rather than creating duplicate resources and services. Project C.A.R.E. staff are working towards improving the efficiency of the overall care delivery system by integrating funding from other sources, such as the North Carolina Family Caregiver Support Program, Consumer-Directed Long-Term Care, and the Home and Community-Based Care Block Grant. In this way, Project C.A.R.E. improves coordination and communication while strengthening the ability of the long-term care system to identify unmet caregiver needs.

Second, the creation of Respite Impact Assessment Teams (R.I.A.T.’s) further enhances resource sharing and planning. R.I.A.T.’s are local consumer and provider committees set up to provide program guidance in each targeted county. Over time, these planning and evaluation

groups will merge with existing regional and county advisory committees for caregiver support and home and community-based services. As a result, dementia-specific respite care will be better integrated by infusion to strengthen the local long-term care system. The involvement of Project C.A.R.E. in local planning efforts appears to be an important strategy to sustain dementia-specific respite beyond the initial federal demonstration period.

Third, Project C.A.R.E. leverages resources through collaboration with other community health and aging organizations such as Hospice. Hospice links families to Project C.A.R.E. and works closely with the Family Consultants to provide supplemental in-home respite and support for clients in the final stages of Alzheimer's disease. Because Hospice offers limited hours of in-home care per week, Project C.A.R.E. becomes a critical dementia-specific adjunct to the limited respite available for caregivers. Hospice also works with Project C.A.R.E. to identify and create volunteer "Support Teams" to expand family-centered community support for clients.

Fourth, Project C.A.R.E. is particularly successful in leveraging community funds. In 2003, the Western Carolina Alzheimer's Association received a three year grant from the Kate B. Reynolds Charitable Foundation to support the Family Consultant position in Forsyth County. Other community organizations and programs also supplement federal funding for Project C.A.R.E., such as Sisters of Mercy of North Carolina and local AAA Family Caregiver Support Programs. A total of 63 agencies in six counties participate in Project C.A.R.E. and benefit from enhanced caregiver training, skills and knowledge as well as greater potential for increased employment of direct care workers.

Finally, and perhaps of greater long-term significance, Project C.A.R.E. provides cost savings by delaying or preventing institutionalization and reducing a caregiver's risk of mental and physical illness or breakdown. Such a direct and immediate fiscal impact could result in

reduced state spending on health and long-term care. It also makes the system more responsive to the needs and preferences of dementia families and more supportive of home and community-based care.

Lessons Learned: Systems Lessons

Service Delivery Models

The success of Project C.A.R.E. from both public and private bases supports the conclusion that local ownership is facilitated by delivery model flexibility (Montgomery, 2003). Each county, AAA region, or Alzheimer's Association service area can and should make an informed decision about the most appropriate base for a dementia-specific respite program: a county DSS, a local Alzheimer's Association Chapter or potentially, another key community-based aging organization.

The Department of Social Services Model

A primary benefit of the county DSS model is the location of Project C.A.R.E. within a larger administrative structure, leading to minimal added costs. The familiarity and close proximity of the DSS Family Consultant with other public programs and administrators expands opportunities for family caregivers. These relationships make it easier to refer or transfer a client who may be eligible for another program contingent upon availability, funding priorities, program requirements and waiting lists. The DSS Family Consultant can supplement Project C.A.R.E. services through the North Carolina Family Caregiver Support Program for other family needs, such as nutrition, incontinence supplies, home repair/modification and transportation services. The DSS model also facilitates access to dementia-specific training,

education and support programs available through the local Alzheimer's Association Chapter and Duke Family Support Program.

Because each DSS can only serve one county, the DSS model is limited in expansion potential. The DSS model is appropriate for a densely populated metropolitan area, such as Charlotte, but may be difficult to implement in a large, multi-county rural area. Nevertheless, adoption of this model in other county DSS adult service units would enhance the ability to meet the needs of caregiver's within an existing infrastructure.

The Alzheimer's Association Model

The Alzheimer's Association model has the advantage of immediate access to a single source of dementia expertise and community programming serving a wide geographical area. By strategically placing a dementia-specific respite program within an Alzheimer's Chapter office, families are directly linked to a wealth of dementia care resources, support services, caregiver training and education as well as the 24-hour National Alzheimer's Association Contact Center. Family Consultants also have the unique benefit of ongoing and direct emotional and professional support of the Alzheimer's Chapter staff. The Consultants can provide extensive dementia-specific information and counseling about the course of the disease and other care-related issues. Families learn more about what to expect and how to better prepare for the future, and Chapters reach families who would not request their traditional support or education services.

The distinct geographical advantages of the Alzheimer's Association model make it particularly useful for less-populated rural areas. Because the local Alzheimer's Chapter serves a large multi-county region, it can expand a program's service area without having to recalculate

funding or split administrative costs. However, there is a significant need for additional program staff to minimize administrative burden.

Central Role of the Family Consultant

The Family Consultant plays a vital role in the success of Project C.A.R.E., offering timely, individualized guidance, counseling, advocacy and education for family caregivers even those who do not take advantage of the respite option. The Consultant is available to provide a neutral but expert third party in mediating family care conflicts. This kind of support for caregivers may buffer the potential negative consequences of limited respite care selection due to shortages in direct care workers and provider agencies, especially in rural areas. Family Consultants offer help with caregiver coping and empower families to take advantage of other relevant services.

The Project C.A.R.E. Family Consultant eases caregiver stress by visiting the home of each family, rather than expecting overburdened, frail or isolated caregivers to visit an office. Family Consultants develop personal relationships with client families and encourage them to become better consumers by insisting on adequate respite care safety, responsibility, dependability and competence. Families also learn appropriate ways to take action if their care standards are not met and are empowered to serve as advocates for their memory-impaired relative. Helping family caregivers select the most appropriate family-specific respite option and facilitating an active family role in evaluating services increases the likelihood that families will learn to trust and accept “outside” help.

The Family Consultant creates an expanded scope and range of family services through local partnerships and collaborative activities. Special programs such as “Caregivers Day Out”,

“Caregivers Unaware” or formal celebrations of national family caregiver events are designed to pamper and/or educate caregivers while providing care and supervision for persons with dementia. Family Consultants work with the Direct Care Workers Association of North Carolina, local Family Caregiver Support Programs, churches, volunteer groups, Hospice and others to supplement Project C.A.R.E. services for both client families and respite providers.

Need for Dementia-Specific Care

A well-documented lesson from Project C.A.R.E. for future aging plans is simply the need for dementia-specific respite care. The increasing prevalence and recognition of dementia as distinct from normal aging creates an opportunity to address the research-documented vulnerabilities of families caring for persons with Alzheimer’s disease and related disorders (National Alliance for Caregiving and National Alzheimer’s Association, 2004). In a recent North Carolina survey, 25% of adults stated that they provide regular care for a person 60 or older. Almost half of these caregivers said they are caring for someone with dementia (BRFSS, 2003). The variability of dementia symptoms, unpredictable disease course, limited family resources and effects of other chronic or acute illnesses, combined with unique behavior and communication challenges, create a need for specialized forms of care and response. By establishing a community-based system that supports dementia caregivers, institutionalization may be delayed, thus lowering high-cost public and family expenditures while significantly sustaining family care capacity.

Because people with progressive dementia become less able to communicate effectively, families often serve as surrogate decision-makers and advocates. There is ample research evidence of the physical and emotional health consequences for family members who provide long-term

care for people with Alzheimer's disease and related disorders (Ory, Yee, Tennstedt, and Schulz, 2000). Increasing age is the greatest risk factor for Alzheimer's and many spousal caregivers are themselves frail or physically compromised. Information about dementia care, while important, is not enough. Creating a sustainable, flexible and comprehensive caregiver support system is essential. Project C.A.R.E. effectively addresses this need within targeted communities.

Project C.A.R.E. client families are given an array of opportunities to learn more about caring for themselves as well as the person with dementia. The Family Consultant identifies appropriate community resources and connects families to dementia-specific training, information and educational materials available through the Duke Family Support Program, Alzheimer's Association, North Carolina Family Caregiver Support Program and AARP Powerful Tools for Caregiving. By providing dementia-specific respite through a program like Project C.A.R.E., North Carolina can create a sustainable caregiver support program that will respect family preference for consumer-directed services and community-based home care.

Lessons Learned: Client/Family Focused Lessons

Consumer Direction in Care

Project C.A.R.E. reflects the nationwide trend toward consumer direction in health care and other social programs. Participants are encouraged, with individualized levels of assistance, to direct their own care and manage the funds allocated for respite care services. Analysis by National Alzheimer's Association policy consultants supports a consumer-directed respite care model. Project C.A.R.E. builds upon the experience of other national consumer-directed care initiatives and could become a North Carolina model for future dementia-specific caregiver support programs.

Project C.A.R.E. families make decisions regarding type of respite service, respite provider, frequency and duration of respite care. This kind of empowerment offers families an emotional boost at a time when they often feel like they have no control. At times, after considering all possible options for care, an overwhelmed caregiver may decide that placement in a residential setting best meets the family's needs. Project C.A.R.E. Family Consultants are then available to provide counseling and help families through this critical transition, teaching them how to continue their family care role by being partners and advocates in the context of facility care.

In the near future, Project C.A.R.E. plans to further expand consumer-directed respite services in rural counties by providing options for individual contractors. The option for private respite care is an improvement to the often-limited selection of agency providers. Although the new alternative will require increased oversight and vigilance from consumers and Family Consultants, other states have successfully experimented with this program feature with no documented increase in fraud or exploitation (Montgomery, 2003).

A Flexible Caregiver Program

The flexibility of Project C.A.R.E. is critical to the program's effectiveness. Although there is an annual spending cap for respite funds, Project C.A.R.E. clients are not limited to a specific period of time, type of respite service, or certain number of respite care hours per week or month. As a result, families can receive respite support that is tailored to their needs and preferences. Project C.A.R.E. also demonstrates flexibility by not imposing service reimbursement limits. The Family Consultant compares reimbursement rates with that of other social programs to make sure they are consistent, but otherwise allows for differing rates if

needed. This type of flexibility encourages families to use their resources more efficiently when purchasing respite care services.

Finally, Project C.A.R.E. demonstrates flexibility in eligibility requirements. The program does not apply age limits, income or resource caps on eligibility, which is a barrier to other social service and public health care programs. Furthermore, Project C.A.R.E.'s link to the Alzheimer's Association provides access to valuable information and resources, regardless of financial means.

A Portal for Long-Term Care Services

Perhaps one of the most important benefits of Project C.A.R.E. is that it serves as a portal for multiple caregiver and dementia-specific services. The availability of immediate, individualized help and funding through Project C.A.R.E. attracts families who could potentially benefit the most and would otherwise fall through the cracks of traditional long-term care, aging and social service systems.

The lack of traditional eligibility requirements for enrollment in Project C.A.R.E. enables the program to serve families who would not know how or may not be willing to get help any other way. Offering a specific subsidized service attracts families who are unlikely to respond to an offer for "free" or "volunteer" services and may not call an Alzheimer's Chapter or Helpline for information and support. Project C.A.R.E. is a point of entry in a "no wrong door" service system and succeeds in attaining outreach goals that traditional aging services consider hard to achieve. The Family Consultant provides counseling and referral services to families regardless of their eligibility to enroll in Project C.A.R.E. and as a result, the "portal" services of Project C.A.R.E. have been extended to over 380 additional families.

Project C.A.R.E. is also a “portal” to Alzheimer’s Association support groups. Once families receive respite care, they are often more willing to connect with peers and create family-centered support networks. In addition to providing ongoing emotional support and education, family support groups reinforce appropriate service use and provide access to consumer information about quality of services.

Future

Research indicates that timely use of respite with appropriate professional guidance, counseling, family education and caregiver support can delay nursing home placement an average of 10 months (Mittelman, 1996). Project C.A.R.E. utilizes community connections to deliver cost-effective, dementia-specific services to family caregivers. These services can be provided in a home or community-based setting, thus delaying institutionalization and strengthening the family’s ability to provide quality long-term care.

Infrastructure building and systems change take time and ongoing funding is critical to insure statewide success and sustainability. The National Alzheimer’s Association’s “2004 Public Policy Program to Conquer Alzheimer’s Disease: From Hopeless to Hopeful” urges expansion of the AOA ADDGS Program to all fifty states. In the U.S. Congress, Senators Mikulski and Bond propose increasing funding for the ADDGS Program, which provides core financial support to Project C.A.R.E. These efforts demonstrate growing national support for more comprehensive caregiver programs with dementia-specific components, such as North Carolina’s Project C.A.R.E.

Project C.A.R.E. clearly demonstrates feasibility and value-added benefits. The lessons learned through the experience of Project C.A.R.E. can help inform the overall home and

community-based care system. The demonstration program meets the intent of the North Carolina Institute of Medicine Long-Term Care Task Force Report, submitted to the Department of Health and Human Services, to support consumer-directed coordination of local service systems. Given the expected increases in persons at risk for dementia, anticipated declines in available family caregivers, and lack of a coherent long-term care system, North Carolina can expect increasing unmet needs for dementia-specific services. Through the Project C.A.R.E. model, North Carolina is strategically placed to become a national leader in creating a seamless, coordinated dementia-capable system of family-centered, caregiver-focused long-term care services.

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